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Long-term impact of irritable bowel syndrome: a qualitative study

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Aim: To explore how irritable bowel syndrome (IBS) impacts on patients' lives in order to explain the reported reduction in quality of life (QOL). **Background:** IBS affects 10–20% of the population and over half of the people with the condition consult in primary care, with many consultations ending unsatisfactorily. IBS is known to have a detrimental effect on the QOL, though the mechanisms through which this is affected are poorly understood. A greater understanding of the patient experience of IBS would facilitate better healthcare provision. **Methods:** Eighteen semi-structured, in-depth interviews were undertaken in the West Midlands, United Kingdom from August 2006 to March 2008. Interviews were carried out until data saturation was achieved. All interviewees had previously taken part in one of the two recent primary care-based IBS studies and were long-term sufferers of IBS. Participants were purposively sampled to capture a range of experiences and included both genders, a range of ages, symptom severity scores and IBS sub-types. **Findings:** In contrast to the previously reported 'worried well' label, participants reported integration of the disease into their lives to the extent that it became a part of their identity. Even so, IBS did at times prevent their participation in everyday activities. Strategies used by participants to manage symptoms were an integral part of daily living and events which threatened routine coping strategies caused stress and exacerbated symptoms. Both adaptive and maladaptive coping strategies were identified. These were in part patient created, but for many incorporated advice or medication provided by their doctor. The findings not only confirm the extensive impact of IBS on daily living but also expose the additional impacts of IBS on emotional well-being and self-identity. The reduced QOL reported in previous studies may be an underestimate of the impact of IBS on patients' lives as patients integrate coping mechanisms completely into daily living.

Key words: irritable bowel syndrome; patient experience; qualitative; quality of life

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Introduction

Irritable bowel syndrome (IBS) is the most common functional gastrointestinal disorder of the developed world (Chang, 2004). Its prevalence in the general population is estimated to lie between

10% and 22% (Jones and Lydeard, 1992; Kennedy *et al.*, 1998; Hungin *et al.*, 2003; Wilson *et al.*, 2004). Although it is likely to be closer to 10%, as studies reporting higher figures are biased through selectively assessing gastrointestinal symptoms, this still translates into annual NHS care costs of £45.6 million (Inadomi *et al.*, 2003). The condition gives rise to a substantial workload in both primary and secondary care, with one-third to one-half of IBS patients consulting a general practitioner (GP) at least once (Jones and Lydeard, 1992; Wilson *et al.*, 2004), and

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around 30% of these being referred to a specialist (Thompson *et al.*, 2000).

IBS is a chronic, relapsing and often lifelong disorder whose long-term morbidities cause insomnia, anxiety and lethargy (NICE, 2007), leading to time off work (Akehurst *et al.*, 2002), avoidance of stressful or social situations and an associated and repeatedly documented reduction in the quality of life (QOL; Akehurst *et al.*, 2002; El-Serag *et al.*, 2002; Chang, 2004; Halder *et al.*, 2004; Pare *et al.*, 2006). The EQ-5D scale, a validated measure of health-related QOL (Akehurst *et al.*, 2002; Pare *et al.*, 2006), has been used in several studies to estimate the QOL of a particular patient group. Collectively, these studies show that IBS patients have a QOL similar to that seen in patients with lower back pain (Brazier *et al.*, 2004; Lamers *et al.*, 2005; Pare *et al.*, 2006) and ankylosing spondylitis (Kobelt *et al.*, 2006), and worse than that seen in patients with gastro-oesophageal reflux disease (Kartmen *et al.*, 2004). It has even been suggested that the impact on the QOL experienced by patients with IBS may be similar to that experienced in congestive heart failure (Whitehead *et al.*, 1996).

The pathophysiology of IBS remains poorly understood and there is an absence of effective treatment options (Horwitz and Fisher, 2001; Talley and Spiller, 2002). This, together with the significant demand IBS places on health service resources (Pare *et al.*, 2006), is a source of frustration for doctors who are unable to provide clear evidence and advice to their patients and have to form their own experienced-based views and management approaches towards IBS (Dixon-Woods and Critchley, 2000).

Dixon-Woods and Critchley (2000) showed that GPs tend to hold both 'public' and 'private' views regarding IBS. Public views are based on a textbook definition, usually including a list of symptom criteria, while private views tend to be based on the application of a psychosocial model and the labelling of IBS patients as 'the worried well' (Dixon-Woods and Critchley, 2000). Where doctors hold these private views, the doctor-IBS patient relationship may be compromised, and patients may report being left feeling that their symptoms have been trivialised (Dixon-Woods and Critchley, 2000; Bertram *et al.*, 2001). IBS patients who have a poor relationship with their doctor have been shown to have low compliance

with treatment, to consult multiple practitioners and to force through unnecessary, invasive and expensive clinical tests (Meadows *et al.*, 1997; Dixon-Woods and Critchley, 2000). Other patients stop consulting, resulting in their self-medicating or suffering in silence in the community (Jones and Lydeard, 1992; Dixon-Woods and Critchley, 2000; Bertram *et al.*, 2001). Little is known of the coping strategies of those who do not seek medical attention (Hahn *et al.*, 1997; Akehurst *et al.*, 2002).

A review of the literature from the last 15 years (using PubMed) indicated that although quantitative data have repeatedly demonstrated that IBS reduces the QOL (Akehurst *et al.*, 2002; El-Serag *et al.*, 2002; Chang, 2004; Halder *et al.*, 2004; Pare *et al.*, 2006), there is little robust qualitative research exploring the range of mechanisms through which QOL is affected. Questionnaire studies that have attempted to evaluate the impacts of IBS are highly structured and preclude any patient experiences that were not anticipated by the researchers (Pare *et al.*, 2006; Lacy *et al.*, 2007). One less structured study that aimed to explore the IBS patient perspective used a postal questionnaire with a single open question (Bengtsson *et al.*, 2007). Without the use of full interviews, such methodology produces qualitative data that are lacking in depth and have not allowed the researcher to clarify or probe for the true meaning. Another study, aiming to explore the impacts of IBS, sampled just seven female students, some of whom had a diagnosis of inflammatory bowel disease (Schneider and Fletcher, 2008).

Other qualitative studies have been too focused in their approach, exploring patients' beliefs about either the cause of their disease, the doctor-patient relationship or the effects of dietary changes on symptoms (Meadows *et al.*, 1997; Dixon-Woods and Critchley, 2000; Fletcher and Schneider, 2006; Jamieson *et al.*, 2007). Such studies fail to explore the impact of IBS on daily life in a broad context. However, one recent qualitative study, which aimed to understand patients' explanatory models for IBS, gave a clearer picture of the impact that IBS has on daily living. The study found that IBS had significant dampening effects on daily life and that patients went to great lengths to prevent the condition from doing so (Casiday *et al.*, 2009). Moreover, both this study and a recent focus group study revealed

that patients did not discuss with their doctors the full extent to which their IBS affected them, leaving doctors relatively uninformed of the impacts of this condition (Casiday *et al.*, 2009; Drossman *et al.*, 2009). However, no previous paper has fully explored the complex psychosocial consequences or challenges to personal identity and role, which arise from disease impact on daily living and adaptation. There has, furthermore, been a tendency to use a medical framework in design and analysis in previous studies, which has perhaps limited their ability to comment fully on the personal impacts of illness.

Therefore, this study, through the use of in-depth interviews, aims to build on what is known about the daily impacts of IBS, and highlight the long-term effects of IBS on patients and the psychosocial consequences of the illness. The study focuses on individuals who have suffered with IBS for many years as it is this group of patients that represents the greatest challenge to the primary healthcare system. We have consciously avoided using a medical framework in analysis to ensure that patient experience can be fully portrayed. Enhanced understanding of the impacts of the condition will facilitate future patient management and may help to raise the profile of IBS on the research agenda.

Methods

A qualitative approach using semi-structured interviews was adopted. Participants were recruited from IBS research databases of community-based patients. Sampling patients who had already taken part in IBS research offered several advantages. It ensured that the IBS status of the patients had been confirmed, that demographic and symptom data were available on each participant, enabling purposive sampling, and that a high positive response rate could be expected.

Participants from two recent studies were eligible to be interviewed. The first study, an IBS prevalence study (Wilson *et al.*, 2004), had subsequent follow-up data that enabled identification of 'chronic IBS sufferers' who matched Rome II diagnostic criteria in both 2002 and 2006. The second was a functional food trial that aimed to determine the value of consumption of probiotic yoghurts in IBS (currently in analysis). Inclusion criteria for this trial were a clinical diagnosis of IBS (confirmed by a specialist or GP) or the

satisfaction of the ROME III criteria when assessed by questionnaire. Both samples were recruited through primary care databases and are therefore believed to represent the condition spectrum diagnosed and managed in this setting.

Fifteen individuals were initially contacted from the prevalence study with a further 20 invited from the functional food trial once the initial data collection was complete. All 35 IBS research participants had given permission for their contact details to be retained. Individuals were selected purposively, to include a range of ages, genders and symptom profiles (IBS-subtype (Tillisch *et al.*, 2005) and severity (Francis *et al.*, 1997)), with the aim of capturing a wide variety of patient experiences (Todres, 2005).

A letter of invitation, a patient information sheet detailing the purpose of the study, a telephone number in case of query, a reply form and a freepost envelope were sent to these patients, of whom 20 agreed to participate. Two of these were not immediately contactable, and were not pursued further as data saturation had been achieved. Patients were contacted by telephone and an interview arranged in their homes at their convenience. Interviews were conducted by either author; both were female, a non-clinical researcher and a medical student, respectively. Ethics approval for the study was granted by Wolverhampton Local Research Ethics Committee (LREC) and Nottingham LREC.

Before the interview, each participant gave written consent for the interview to be audio-taped, having been assured of confidentiality by the researcher. Interviews lasted around 40 min, ranging from 20 to 70 min. They were based on a semi-structured topic guide (see Appendix, Figure 1) that aimed to explore the IBS patient experience through discussion about the impact of their IBS on everyday life, fears, beliefs and coping strategies. All issues raised by the participants were expanded upon to ensure that patient experience was fully captured. Data were collected and analysed iteratively, which allowed the interviewer to follow participant responses and enabled a gradual focusing on emergent themes from one interview to the next. The concurrent collection and analysis of the interviews also allowed for further sampling to identify confirmatory or deviant cases and served as a validity check (Murphy *et al.*, 1998).

All interviews were transcribed in full and imported into NVivo software for thematic analysis. One researcher (RF) systematically reviewed the tapes and transcripts to identify key and recurrent words and themes and applied initial coding to the data. A second researcher (LR) reviewed the initial coding and discussion among the two researchers was used to consolidate ideas and confirm the accuracy of the emerging themes. Further recoding, consisting of the constant comparison of coding units and categories in order to develop higher order categories or 'main themes', resulted in the construction of a best-fit thematic framework for the data (Ritchie *et al.*, 2003). The goal was to describe the complete range of patient experiences rather than to expect a convergence or consensus of the data set. Themes arising from final interviews fitted codes that had already been described and established and no new codes were developing. We were therefore confident that data saturation had been achieved.

In tandem with the formal data collected at each interview, an observation diary was kept by the interviewer who recorded reflections on the interviews and notes on analytical thoughts and decisions as they occurred. This ensured transparency between the researchers.

Results

Eighteen participants were interviewed and their characteristics are summarised in Figure 2 (see Appendix). The IBS-QOL (Patrick *et al.*, 1998) scores of the chronic sufferers (range 44–111) and the IBS symptom severity scores of the functional food trial participants (range 77–440) indicate a reasonable QOL, but with a wide variation between participants. Five main themes emerged from the interviews: symptom experience and the impact of IBS on daily living, emotional well-being, health service use and identity. All themes emerged spontaneously from the data and were present in both men and women. A thematic framework for the impacts of IBS is shown in Figure 4 (see Appendix). Quotes from the raw data are displayed in Figures 3, 5, 6, 7 and 8 (see Appendix) and themes supported by them are indicated by figure number and quote reference throughout the results section.

Symptom experience

Abdominal pain was the most commonly experienced symptom and was frequently cited as the worst aspect of the condition to cope with (3a, 3b). Mothers described the pain as worse than labour pain (3c). The pain had numerous consequences – it caused a loss of concentration, a lack of sleep, fainting, vomiting, the inability to move or lift and therefore work, a low libido and depression. Constipation, which could last for weeks at a time (3d), was associated with the worst of the pains and resulted in bloating, which was a cause of physical discomfort and embarrassment (3e). Diarrhoea was less painful but often extremely urgent (3f, 3g). Symptoms were unpredictable and participants remained uncertain about specific triggers and warning signs (3h). Participants also described IBS as having an impact on their general health with many suffering exhaustion, temperatures, nausea and depression (3i, 3j).

Impact on daily living

Participants described how IBS caused them to adopt either adaptive changes or avoidance strategies, both of which had significant impacts on their daily living. Adaptive changes allowed participants to maintain a fairly normal level of functioning, whereas avoidance tended to reduce this ability. However, at times, adaptation and avoidance were inadequate coping mechanisms and IBS became disruptive. Impacts on daily living were surprisingly consistent across sub-types of IBS; for example, social activities were sometimes compromised by the need to be near private toilets, but this applied both to those with diarrhoea (urgency) and constipation (to prevent embarrassment from flatulence).

Adaptive strategies were in part patient created but for many incorporated the advice or medication provided by their doctor (5a, 5b). Pragmatic solutions were often adopted, such as carefully planning routes to include toilets, waking up earlier to allow bowel function to normalise before leaving the house, carrying spare underwear, air freshener and painkillers and planning the day around times when the worst symptoms were anticipated (5c). When conventional medication was inadequate to control the symptoms, participants sought out alternatives in the shape of alternative therapies and dietary modifications (5d).

Psychological coping techniques were also apparent. These included maintaining hope, seeking comfort in family and friends, maintaining a sense of humour and making a conscious effort to relax. Humour was particularly effective as it enabled participants to share their knowledge and fears with other people (5e). Almost all participants stated that keeping impacts to a minimum was a case of 'mind over matter', suggesting the importance of support from both family and healthcare practitioners (5f).

Many participants indicated that they had their own technique for inducing bowel movement, which was used either to prepare for a normal day or as a reaction to an extreme or unpredictable situation. Such techniques ranged from caffeine, nicotine and exercise through to abdominal massage but also included physically removing the stool with a gloved hand (5g, 5h). Strategies used by participants to manage symptoms were an integral part of daily living, and changes or events that threatened these routine coping strategies caused stress, which would further exacerbate symptoms.

Avoidance strategies occurred when symptoms presented, or when there was a fear that the symptoms would present, at a particularly inconvenient or embarrassing time. Avoidance could occur alongside adaptation. Participants reported avoiding certain clothes, public toilets, restaurants, holidays, new situations where toilet facilities were unknown and even at times leaving the house (5i–5k).

In spite of the use of both adaptive and avoidance strategies, participants described four aspects of life that were significantly disrupted by IBS. These were basic functioning (walking, working and sleeping), relationships, self-image and psychological well-being (5l–5p). Excessive bloating caused participants to worry about their appearance (5l). Partnerships were strained due to participants suffering low moods, low self-esteem and consequent low libido and through finding sex physically uncomfortable (5m, 5n). All of these, together with the lack of available treatment, led to despair and depression in some individuals (5p).

Emotional impact

Participants described a range of negative emotions attributed to their IBS. These included

depression, fear, anxiety and embarrassment (6a, 6b). Depression occurred when participants had suffered for a protracted period and had been unsuccessful with treatment (6c). Many participants described that fearing IBS was a misdiagnosis and that something more sinister had been missed (6d). This fear was strengthened by extreme symptoms, a family history of bowel cancer or something similar and a lack of faith in the health service (6e–6g). Situational fears, in which the participant feared their symptoms presenting at an inconvenient time, were also common. Many participants reported emotional cycles in which fear led to stress and consequent exacerbation of symptoms, which acted to further increase the fear (6h). Participants felt that it was therefore important for doctors to understand their fears in order for progress to be made with their treatment (6g).

Impact on health service use

Most participants reported an alienation from the health services and three principal reasons emerged as to why this was the case (Figure 4). The first was a poor doctor–patient relationship. Participants described doctors who undervalued symptoms, contradicted each other, failed to build a relationship with them and who gave limited or no explanation about how to manage IBS (7a–7c). The second was the belief that the NHS could offer no help for IBS based on past experience or on the experiences of others (7d, 7e). Third, participants attributed the onset or worsening of their symptoms to previous medical care (7f, 7g). In contrast, participants who were happy with their treatment described doctors who had fully investigated their fears and whose support had helped put their minds at rest (6g).

Impact on identity

Many participants reported integration of the disease into their lives so completely that it had become a part of their sense of identity. Participants explained that because of the length of their suffering or because they coped through normalising their symptoms, they were sometimes unaware of the everyday adjustments they made (8a–8d). In some cases, this normalisation was doctor reinforced (8e). However, there were also individuals

who believed their IBS threatened aspects of their identity, such as their role as a mother, partner or friend (8f–8h).

Discussion

In accordance with what is already known about the patient experience of IBS (Dixon-Woods and Critchley, 2000; Bertram *et al.*, 2001; Lacy *et al.*, 2007; Drossman *et al.*, 2009), the majority of participants in this study reported their IBS symptoms to be painful and unpredictable and therefore having a significant impact on their QOL. Many previous quantitative studies have shown that IBS results in a reduced QOL, (Akehurst *et al.*, 2002; El-Serag *et al.*, 2002; Chang, 2004; Halder *et al.*, 2004; Pare *et al.*, 2006), and this study gives an insight into the mechanisms through which QOL is affected. It confirms recent findings of the extensive impact of IBS on daily living (Casiday *et al.*, 2009), but has also exposed the additional impacts of IBS on emotional well-being and self-identity, which arise either because of the impact on daily living or adaptation and avoidance strategies.

IBS impacted on daily living through the adoption of coping strategies used by participants to manage their symptoms, reconfirming recent findings by Casiday *et al.* (2009) that patients make great efforts not to allow the condition to take over their lives. Coping strategies were in part patient created but for many incorporated advice or medication provided by their doctor. This is in contrast to previous research, which found that patients are left frustrated by the ineffective advice they receive from doctors and therefore tend to be non-compliant with it (Dixon-Woods and Critchley, 2000). These findings highlight the importance of doctors in helping patients with IBS achieve optimal symptom management. Coping strategies were an integral part of daily living and changes or events, which threatened their completion caused stress, which further exacerbated symptoms. It has long been established that IBS is associated with anxiety and depression (Herschbach *et al.*, 1999; Nicholl *et al.*, 2007; Pare *et al.*, 2007), and participants explained that this occurred when coping strategies were inadequate or they remained fearful of the emergence of unpredictable symptoms. This

fear explains the recent findings by Drossman *et al.* (2009) that IBS can restrict activities even when symptoms are not actively present. Previous studies have indicated that IBS is an example of somatisation, whereby anxiety and/or depression can cause IBS (Locke *et al.*, 2004; Nicholl *et al.*, 2007). However, our findings indicate that patients feel the opposite to also be the case, namely that IBS can trigger depression and anxiety.

In accordance with previous studies (Dixon-Woods and Critchley, 2000; Lacy *et al.*, 2007; Casiday *et al.*, 2009), the fear that IBS was a misdiagnosis and that something more sinister (usually bowel cancer) had been missed was apparent in many of the participants in this study. Several participants attributed this fear to perpetuating a vicious cycle in which their fear caused them stress, causing their symptoms to worsen, which acted to strengthen their initial fear. Vicious cycles have been described in previous IBS research (Dixon-Woods and Critchley, 2000) and the data from this study add that for many patients it is the underlying fear of misdiagnosis that triggers the cycle. This finding reinforces the importance of doctors who understand the concerns of this patient group in enabling their optimal management.

In accordance with previous qualitative research on IBS (Meadows *et al.*, 1997; Dixon-Woods and Critchley, 2000; Bertram *et al.*, 2001; Lacy *et al.*, 2007), the present findings also highlight patients' feelings of being let down by the health services, and go further to explore the reasons why this is the case. Participants complained of a poor relationship with their GP, a lack of information from their GP and medical advice that had worsened their condition. For example, the standard advice to increase dietary fibre had exacerbated symptoms in some participants, a finding supported by previous research (Casiday *et al.*, 2009). This provides some explanation as to why it is that almost half of the people with IBS do not consult a doctor (Jones and Lydeard, 1992; Wilson *et al.*, 2004). Furthermore, this study provides a clearer understanding of the complex coping strategies adopted by these non-consulters in the community, data that had previously been lacking (Hahn *et al.*, 1997; Akehurst *et al.*, 2002).

In contrast to the previously reported 'worried well' label (Dixon-Woods and Critchley, 2000), many participants reported integration of the

condition into their lives to the extent that it became a part of their sense of identity. However, other participants, or at times the same participant recalling a different situation, felt that because IBS prevented their involvement in everyday roles and activities, it became a threat to their identity. This mirrors the observation made by Dixon-Woods and Critchley (2000) that doctors distinguish between 'good' and 'bad' IBS patients. 'Good' patients accept their diagnosis while 'bad' patients resent their IBS label, reflecting the integration or confrontation observed in patients in this study. In contrast to the doctors' fixed views, patients felt that this classification was flexible in that they could have both 'good' and 'bad' days.

Our findings suggest that the reduced QOL highlighted in previous studies (Akehurst *et al.*, 2002; El-Serag *et al.*, 2002; Chang, 2004; Halder *et al.*, 2004; Pare *et al.*, 2007) is an underestimate of the overall impact of IBS since patients integrate IBS into their lives to the extent that it becomes a part of their sense of identity. This study therefore reconfirms the finding of Casiday *et al.* (2009) that patients are likely to underreport the extent to which IBS affects their lives. However, Casiday *et al.* (2009) reported that this was because patients adopted a stoical approach to coping with their IBS. This is in contrast to our own data that suggest that this is less to do with the patient's stoicism and more to do with patients allowing the condition to become a part of their sense of identity. Moreover, the replication of this result is in itself important and further suggests that IBS has a much wider impact than previously reported.

Strengths and limitations

This study was strengthened by the use of in-depth interviews and by its exploration of the patient perspective. Purposive sampling enabled the exploration of the impact of IBS on individuals not only with differing demographic profiles but also with different symptom profiles and severity scores. This sets it apart from many previous qualitative IBS studies which have chosen to focus exclusively on women (Dixon-Woods and Critchley, 2000; Bengtsson *et al.*, 2007; Jamieson *et al.*, 2007; Schneider and Fletcher, 2008). Although reliability may have been compromised by the use of a single coder for initial coding, the impact of this will have been minimised by the

use of a second researcher to review the raw data and input to the developing coding framework.

Recruitment for both previous studies was through primary care, and therefore the sample in this study is broadly representative of those that consult here. However, it must be acknowledged that those with worse symptoms are always more likely to participate in research, and therefore the experiences described in this study are likely to reflect those of individuals with more severe IBS or IBS that impacts on life more significantly. While the sample was limited to those who had partaken in previous IBS research, and therefore may not be generalisable to all people with IBS, this recruitment method allowed the study to focus on people who were long-term sufferers of IBS. The study therefore gives an important insight into the impact IBS has on chronic sufferers; a group of patients whom the primary healthcare system has struggled to accommodate so far.

Implications for future research or clinical practice

Previous research has reported a need for medical professionals to have a greater insight into the impact of IBS on patients' lives (Dixon-Woods and Critchley, 2000; Bertram *et al.*, 2001; Bengtsson *et al.*, 2007). This study reconfirms recent findings of the extensive impact of IBS on daily living (Casiday *et al.*, 2009), but has also exposed the additional impacts of IBS on emotional well-being and personal identity. These findings provide doctors with a greater understanding of the impacts of this condition with which they can aim to foster better relations with this patient group. In particular, this study has highlighted that patient fears are likely to compromise the successful management of IBS and doctors should therefore explore patient fears from the outset.

Future research should investigate factors associated with the adoption of maladaptive (avoidance or disruptive) coping strategies, what can be done to prevent this, and whether or not the coping strategies identified by this study can be generalised to other psychosomatic diseases.

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Appendix

<p>General explanation of their experience of IBS</p> <p><i>Could you tell me about your irritable bowel syndrome?</i></p> <p>When did it begin? How did it begin?</p> <p>Were the first symptoms preceded by any other changes in your life? Do you have any idea what causes your symptoms? Did you have any concerns about your symptoms before diagnosis?</p> <p>Have you ever consulted a doctor about these symptoms? If so when did you first consult and why? If not, why not? What investigations? How quickly was it diagnosed? How was it first managed?</p> <p>Have the symptoms changed over time?</p> <p>How often does it cause you problems currently?</p>
<p>Medications/ other therapies</p> <p><i>What medications/ other therapies have you tried for your IBS?</i></p> <p>Where did you first hear of this treatment?</p> <p>How often do you use it and how does it help?</p>

Figure 1 Interview topic guide
Primary Health Care Research & Development 2011; **12**: 52–67

<p>Lifestyle changes</p> <p><i>Could you describe any changes that you have made in your day to day life that help you to cope with the disease?</i></p> <p>Any foods that you avoid/ deliberately eat?</p> <p>Any changes in your schedule?</p> <p>How do you feel about leaving the house? Do you take extra precautions when you are in a public place? What exactly are these precautions?</p> <p>Do you work? How has IBS affected your work life? Have you ever had any time off work due to IBS symptoms?</p> <p>Have you gained any routines that are designed either to help you to pass stool or that prevent you from needing to pass stool at an inappropriate time?</p> <p>Can you tell me about an occasion where IBS has significantly affected your life eg. an embarrassing situation/ spoilt event?</p>
<p>Questions on pain</p> <p><i>Describe a typical episode of pain for me.</i></p> <p>What happens when you are in pain? Can you continue what you were doing?</p> <p>How often do you feel pain? How long does it last?</p> <p>When does the pain occur? Are there any warning signs that you associate with it?</p> <p>How would you rate this pain? How disabling is the pain?</p> <p>Is there anything you can do to relieve the pain? How effective is this?</p>
<p>Any other issues</p> <p><i>Are there any other issues we haven't addressed that you would like to mention?</i></p>

NB. Questions in italics were routinely asked to introduce a topic to the participant and the remaining questions were used as prompts if necessary. As the interviews were semi-structured further expansion of issues raised was undertaken.

Figure 1 (Continued)

	'Chronic Sufferers' (n = 11)	Functional Food Trial Participants (n = 7)
Age Range (yrs):	37-84	22 - 72
Gender split:	10 females, 1 male	4 females, 3 males
IBS Subtype:	3 constipation, 3 diarrhoea, 5 mixed	4 constipation, 3 mixed
IBS Severity:	QOL score* range: 44 – 111	IBS SSS** range: 77 – 440

* IBS-specific quality of life (QOL) score: Scores from 34 – 170, with higher scores indicating a poorer quality of life of the IBS patient (Patrick et al., 1998).

** IBS-specific Symptom Severity Score (SSS): Scores range from 0 – 500, with higher scores indicating more severe IBS symptoms (Francis et al., 1997).

Figure 2 Participant characteristics

- 3a.** “Because when the pain comes, I mean I go all hot, sometimes I can pass out with the pain. And I really can’t hack that.” (P4; Female, 37, IBS-C)
- 3b.** “I mean the feeling is as if you’re on fire, as if you’re burning. If you’ve got an open sore on the outside then you can put cream on to soothe it. It feels like that inside but there is nothing you can put on to stop it.” (P18; Male, 70, IBS-M)
- 3c.** “It’s like a real strong, I’d almost say like a contraction, like labour I mean. I have had less pain with labour.” (P5; Female, 52, IBS-D)
- 3d.** “But if I don’t take anything to help me go to the toilet, I don’t go to the toilet. And the longest period of not going to the toilet was nearly five weeks.” (P11; Female, 42, IBS-C)
- 3e.** “I just always feel like I’m full of gas, I can never go to the loo. It’s really embarrassing.” (P13; Female, 39, IBS-M)
- 3f.** “Like when the pain comes on, the crunching pain comes on, I’ve literally got seconds to get to a toilet.” (P5; Female, 52, IBS-D)
- 3g.** “I’ve had to leave shopping, put her in the car, drive home, grab her out the car, run upstairs and sit her in the bathroom in the car seat, and that was it then I was there for ages. [Patient laughs] I left my car doors wide open and everything [Both laugh] because it was that urgent, just get in there.” (P1; Female, 38, IBS-M)
- 3h.** “What happens is it goes from one end of the scale to the other end of the scale. It goes from can’t go for two or three days to... go four or five times in one day. That’s how it is.... there’s no explanation.” (P18; Male, 70, IBS-M)
- 3i.** “Well sometimes you’re run down with it. Other times, especially when you got, when I have to go and lie down, its oh... sometimes I’m thinking, ‘Let me go, let me go.’” (P2; Male, 84, IBS-D)
- 3j.** “Erm.. and the pain will get that bad that I get so hot I’m sweating, I can feel sweat going down my back and I’ll be sick sometimes.” (P10; Female, 38, IBS-M)

Participants are identified as follows: (Participant Number; Gender, Age in years, IBS subtype*)

*IBS subtypes: IBS-C = IBS with constipation. IBS-D = IBS with diarrhea. IBS-M = IBS with mixed symptoms. Subtypes defined according to ROME III criteria (Tillisch et al., 2005)

Figure 3 Symptom experience.

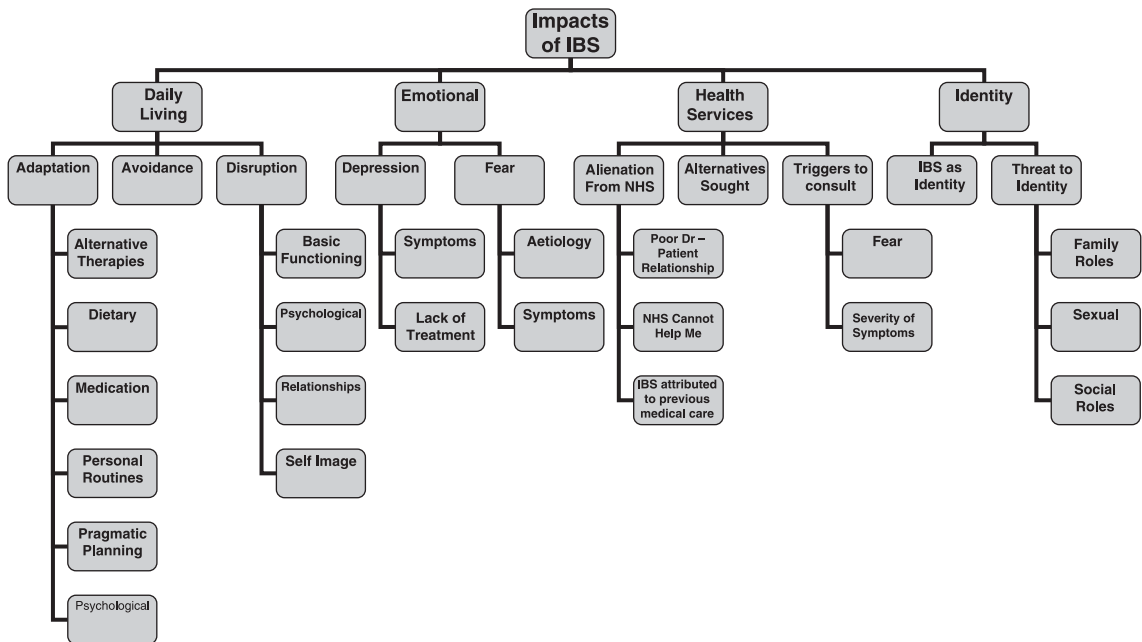


Figure 4 Thematic framework displaying the Impacts of irritable bowel syndrome (IBS)

Adaptation Strategies
<p>5a. “But if I’ve got the time now I like to get up in the morning, have a few cups of coffee or tea, so I can, but you know, sometimes its two hours before I go to the toilet.” (P12; Male, 51, IBS-M)</p>
<p>5b. “At the moment I take syrup of figs and I take it, a spoon of it every night before I go to bed, but if I do that I go to the toilet.” (P11; Female, 42, IBS-C)</p>
<p>5c. “After that I got used to it, you know, I had to find places really where I knew where the toilet was just in case I got to run.” (P2; Male, 84, IBS-D)</p>
<p>5d. “Well I had already been though all the standard pills and potions that you can get from the chemist and Imodium didn’t work after, it did for a little while, but then it didn’t and it did for a little with another one and it didn’t umm...So I tried this alternative health therapies erm.. I tried hypnotherapy ermm.. I’ve tried ermm acupuncture ermm massage, aromatherapy massage.” (P10; Female, 38, IBS-M)</p>
<p>5e. “Quite a few of my friends have got it as well you know so when, we’ve been talking about it like we do [Patient laughs] you know you say “oh well is this good” and that’s why I said that you know, one of them said about red meat.” (P5; Female, 52, IBS-D)</p>

Figure 5 Impact on daily living

Adaptation Strategies	
5f. "Mind over matter, isn't it, mind over matter, I mean while I can still deal with it then you know I will just carry on, you never know it might get better."	(P1; Female, 38, IBS-M)
5g. "I have cup of coffee and a cigarette in bed in the morning, before I get out I go."	(P1; Female, 38, IBS-M)
5h. "I have, I have on occasions sort of had to pull it out with me hands which isn't... [Laughs]"	(P17; Female, 59, IBS-C)
Avoidance Strategies	
5i. "Err... I suppose now, of a morning, I can honestly say I can't go out of the house until I've been."	(P7; Female, 52, IBS-D)
5j. "I couldn't go in a public toilet. No. Like a club or... no that would just horrify me. If I got a bad one I will not go out, I won't go anywhere."	(P1; Female, 38, IBS-M)
5k. "Well, I mean there are very often days that I will want to go off to do things and I think depending how I feel if I've been and I feel I'm clear I can go, but if I'm not, if I don't I mean I've got an allotment...In this weather, this year, with the summer as it has been, it would have been lovely to be up there [the allotment] at seven when it was nice and any other time really I mean you know, but unless you know, I can't go to, I don't go to places unless I know there is a toilet there."	(P3; Female, 75, IBS-M)
Disruptive Impacts	
5l. "I've always been a fit man. I've always been sports orientated, even with the discomfort... weight lifting, weight training, but then all of a sudden I've got a gut and that is.... I can't handle that... people would think it was a beer belly..."	(P18; Male, 70, IBS-M)
5m. "Well to be quite honest err...[baby making noise]...It does put [Unintelligible word] in the bed room, because it's not nice to feel uncomfortable all the time, because sometimes I can't have intercourse because of the pain."	(P4; Female, 37, IBS-C)
5n. "I mean I have had mishaps, I've had to come back and leave the wife and come and change myself."	(P2; Male, 84, IBS-D)
5o. "No, the only thing is, if it's to do with IBS, the pain in my back, sometimes I can't lift as I should do."	(P17; Male, 72, IBS-C)
5p. "Like but that was like really embarrassing I've got to admit I got upset and I just sat there in the cubicle like really upset with myself and I thought 'oh you get like old age pensioners like this.'"	(P5; Female, 52, IBS-D)

Figure 5 (Continued)

- 6a.** *"And then I would need, well I was sobbing in the bathroom trying to go to the toilet and I would take a senna."* (P1; Female, 38, IBS-M)
- 6b.** *"Not stupidly drunk, but I'd had far too much to drink too early because I was that miserable, how I felt."* (P13; Female, 39, IBS-M)
- 6c.** *"Umm and to be honest I was losing heart cause this was over about three or four years and... I'm going to get emotional... [patient upset/crying]... I did say to him I have given up on it really. Umm... and that was another thing that he suggested actually, erm... antidepressants."* (P10; Female, 38, IBS-M)
- 6d.** *"Erm, well, I just, I was frightened more than anything, looking back at it. It's the same with anything now, the fear of cancer is, it's always, whenever you've got something like this, like it is now, you've always got that in your head."* (P18; Male, 70, IBS-M)
- 6e.** *"I had to get a GP out a couple of times because I wasn't sure if I'd actually got an appendicitis, it was that painful, and I actually passed out a few times with it."* (P13; Female, 39, IBS-M)
- 6f.** *"I see that so often where people haven't investigated that early enough that maybe it could be that so sometimes I think maybe I want to go to the doctors and say "can I have these done just to rule it out" but then... and then I go to the toilet and I think "oh, no everything is ok" so then I put it to the back of my mind but yes I do think about that, yeah."* (P9; Female, 58, IBS-C)
- 6g.** *"I thought well hang on this family history worries me are you sure this is just IBS and I'm sure they probably thought I was being a bit over anxious and bit over the top with it but they said yeah, if you feel that way then we'll arrange for you to have a test at the hospital and what have you, it's not very pleasant but it might put your mind at rest. You know, the less you're worrying about it the less you're going to be affected. So they were quite supportive really."* P13; Female, 39, IBS-M)
- 6h.** *"If I think I haven't been for a week or so then I do start to panic and sometimes I do get anxious that maybe there is something more than just...you know... and then maybe that's like a vicious circle that I'm getting myself up tight that something is wrong and then that makes it worse I really don't know."* (P9; Female, 58, IBS-C)

Figure 6 Emotional impact



Figure 7 Impact on health service use

- 8a.** *"It's one of those things. The thing is that I've suffered this for that many years that it is part of my life, it's annoying, it's hurtful, but it's something that.... I know no different. I do not know any different."* (P18; Male, 70, IBS-M)
- 8b.** *"Then other times you think no maybe that's just the way I'm meant to be."* (P9; Female, 58, IBS-C)
- 8c.** *"I just thought well this is just how I am, I think it was just constant constipation or not very good toilet habit."* (P13; Female, 39, IBS-M)
- 8d.** *"Umm.. no I don't think I really make, you see I might make allowances now but because I'm so used to it I probably don't take any note of it."* (P10; Female, 38, IBS-M)
- 8e.** *"The doctors always said that's really nothing to worry about, its, that's the probably the way I am."* (P9; Female, 58, IBS-C)
- 8f.** *"I can't even let my son sit on my lap when I got pain."* (P4; Female, 37, IBS-C)
- 8g.** *"I mean it even interferes with your sex life because it can be so painful to have sex because if you've got a particularly swollen stomach at the time you've only got to sort of lie in a position where it just catches you and its just like, well you just get like a knifing pain almost, so that's frustrating."* (P13; Female, 39, IBS-M)
- 8h.** *"Then I won't drink or anything, I will just eat what I gotta eat and I will take a couple of paracetamol after, but I find it does interrupt my social life."* (P4; Female, 37, IBS-C)

Figure 8 Impact on identity